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A carer's perspective on medicines optimisation

Barry Jubraj is Clinical Senior Lecturer (Medicines Optimisation), King's College London, and father & carer to Alexander, who has Down's Syndrome and complex medical needs.

I jumped at the chance when invited to give a carer's perspective on medicines optimisation. Not because I wanted to complain or be negative; but instead to encourage all clinicians, but particularly those in my own profession of pharmacy, to really believe that they can make a difference to people like me, a carer and a patient.

So, first, the bad news: I'd really like the pharmacists I meet to think more about how hard it might be to manage medicines for my little boy, who is severely disabled. But the good news is that I firmly believe that pharmacists have the potential to make a much bigger contribution to supporting carers and those with disabilities, with their medicines.

I am fortunate enough (or unfortunate depending on your point of view) to have a number of perspectives on the topic of caring, disability and medicines. I worked as a hospital pharmacist for 25 years, am trained as a teacher and a counsellor; I am a patient with two long-term conditions; and have been a carer latterly for my mother; and more recently for my 9 year-old-son, Alexander. He has Down's Syndrome, a severe learning difficulty, uses a wheelchair, glasses and hearing aids, has thickened fluids and suffers with asthma, thyroid disease and reflux. In this article I will aim to frame my reflections around the four principles of medicines optimisation found in the Royal Pharmaceutical Society Guidance:

<https://www.rpharms.com/promoting-pharmacy-pdfs/helping-patients-make-the-most-of-their-medicines.pdf>

Principle 1: Aim to understand the patient's experience

I've often wondered how curious clinicians are when they see me and my wife Rosemary coming through the door with Alexander. He is in a wheelchair, makes lovely funny noises and to us it's obvious that getting medicines into him or monitoring them isn't going to be straightforward. Alexander's medication routine in the evening is described in a BMJ case report where we outline the regime of two tablets and one liquid dissolved in an eggcup and then thickened.

<http://casereports.bmj.com/content/2015/bcr-2014-208033.full.pdf>

I'm curious to know your reaction when I say that no hospital or community pharmacist, GP, paediatrician or hospital doctor has ever asked us how we manage to get the medicines into Alexander, or any challenges that we face. I've often wondered if any of the reasons below are true:

- Too busy to think about it
- Assume that someone else has sorted it out

- Too scared to ask for whatever reason

You will see from the following video and debrief where we filmed a consultation about Alexander that the pharmacist was curious and willing to ask me how I was getting on.

Commented [v1]: CPPE ref and videos from Lesley with permission

<https://www.dropbox.com/sh/m95tr3nn1a25wqx/AAC6QH1C9C77j1JmJddFwe1La?dl=0&preview=What+would+be+helpful+to+you+right+now+-+Making+a+difference+in+a+short+consultation.mp4>

<https://www.dropbox.com/sh/m95tr3nn1a25wqx/AAC6QH1C9C77j1JmJddFwe1La?dl=0&preview=Making+the+difference+in+a+short+consultation+-+the+experts+debrief.mp4>

I would love all clinicians to be that curious and ask me how I am doing as a carer. Carers often have to make things up best we can – and I have the advantage of being a pharmacist.

Principle 2: Evidence-based choice of medicines

As a pharmacist, I'm used to following guidance and trying to be aware of the evidence behind that guidance. Experience has taught me that medicine is an art as well as a science and that it's important to be pragmatic and practical. Carers often have the best understanding of the 'big picture' of the person they're caring for and a recent example brought this home to us. Alexander's serum ferritin was low and our paediatrician wanted him, quite rightly, to have a course of iron through the GP. Our paediatrician and GP are excellent clinicians and we discussed the risks of constipation that can be much worse for Alexander because of his low muscle tone and low mobility. Although one could argue that a treatment dose of iron is most appropriate, i.e. three times a day, I pushed very hard for a once daily dose, to balance the risk of constipation with restoring the ferritin levels, albeit more slowly, based on the fact that Alexander's haemoglobin was in the normal range. For me as a carer, it was a pragmatic, balanced decision based on my intimate knowledge of Alexander and his wider health picture that we live with day-to-day. We as parents are the ones who toilet him and understands his bowel habit.

Principle 3: Ensure medicines use is as safe as possible

As Alexander's carer, I'm interested in medication safety from two perspectives. Firstly, that the medicines prescribed for him are inherently safe, for example with respect to allergies and interactions. But I'm also concerned about safety with respect to his poor swallow and delayed clearing cough, hence his need for thickened fluids. I also want to be sure that the methods by which I give him his medicines are safe – for example my egg cup technique. This is one reason why the use of 'My Medication Passport' for Alexander has been so helpful.

<https://www.networks.nhs.uk/nhs-networks/my-medication-passport/documents/my-medication-passport-in-bmj-open>

It contains a list of Alexander's medicines which means we don't have to explain them again and again at every medical appointment. It also helps clinicians to consider the existing medication list when prescribing something new. It would be helpful if clinicians did a sense check with me on the safety of Alexander's medication use, which would be a neat overlap with medicines optimisation principle 1.

Principle 4: Make medicines optimisation part of routine practice

As a carer, principle four is about the need for clinicians to develop a culture of being curious, thinking 'outside the box' and delivering excellence in consultation skills from the early years' of clinical practice. I have observed junior clinicians looking somewhat perplexed when they encounter Alexander – hopefully not because of him as a person; but I sense a fear of what they might be asked. Experience is clearly helpful in communicating, but education and mind-set are important. Exposure to carers and their experience can help clinicians to gain valuable insights into the world of being a carer, including the stress, the lack of sleep and the worry. A curious mind-set that can tolerate questions you may not be able to immediately answer can lead to valuable and opportunistic encounters with people like me. It really doesn't matter if you don't know the answer immediately! Taking an interest will help me to feel valued and supported in what is often a lonely existence.

Suggested actions

For curriculum planners and professional bodies:

- Expose trainee clinicians to carers as part of their training
- Ensure that consultation skills training is embedded in clinical training and continuing fitness to practice programmes
- Promote a culture of empathy for patients and carers through effective curriculum planning

For individual clinicians:

- Be curious. Ask someone who may be a carer how they are getting on
- Invite questions and don't worry if you don't know the answer immediately, or if an answer isn't obvious
- Be pragmatic. The answer to the compatibility of Alexander's egg cup mixture is likely to be found only in a laboratory. Use your basic understanding of pharmaceutical science to deliver pragmatic and helpful advice
- Don't say 'I understand'. You don't
- Smile and say hello. Introduce yourself. It makes a real difference to a carer

Word count:

